AN ACT CONCERNING THE USE OF LONG-TERM ANTIBIOTICS FOR THE TREATMENT OF LYME DISEASE

We (my family) suffer from neurological Lyme, Lyme Neuroborreliosis, including psychiatric symptoms.

We were on psychiatric meds, which did help some, until we were diagnosed and treated for our tick-borne diseases. The antibiotic treatment ended completely our psychiatric symptoms. Our daughter was the sickest of us, she missed her full 3rd and 4th grade school years due to symptoms of neuroborreliosis. Her psychiatric symptoms have ended completely since she has been treated with antibiotics. Both our kids were put on psychiatric meds, which increased their weight dramatically, made them groggy and slowed their thinking. Sadly, it is much easier to find a doctor willing to put your child on potentially harmful psychiatric meds than it is to find a doctor that will treat Lyme aggressively with antibiotics. Especially for children. There seems to be no cure for chronic Lyme in adults and there are no studies being done to find a cure because the NIH and CDC are still not sure if there is any possibility chronic Lyme even e xists, despite scientific evidence. Articles of persistent infection can be found here: http://www.lymeinfo.net/lymefiles.html#sci

Our daughter spent 3 1/2 weeks in a locked pediatric psychiatric unit in the summer of 1998. She turned nine years old just weeks before. She was paranoid, delusional, psychotic, suicidal, homicidal, having visual hallucinations, severe confusion, pain in major and small joints, partially lost vision (could no longer read, which she had loved), had severe cognitive regression (which included being unable to add 1+2, literally, and she knew it) and suffered with dementia.

Because she could not attend public school she was placed in a "behavioral program" locally. At this "school" she was physically restrained and put in solitary confinement almost daily for 3 months. There she cried, fought with her very real "ogres", screamed, beat on the matt which was used to contain her, and finally would curl up in a fetal ball on the cold floor in the corner and sob. My husband found her in this "room" one day and removed her from the "school" immediately. She then spent 3 months at home with no schooling available for her.

The list of psychiatric meds she took is extensive. Her psychiatric diagnoses were: bipolar II, anxiety disorder NOS, ADHD, psychosis, R/O schizoaffective, R/O schizophrenia.

Some of her test results; her IQ dropped 45 points in 6 months, two abnormal MRIs both with MULTIPLE lesions throughout the brain, predominately in the frontal lobes, two abnormal SPECT scans showing low blood flow, hypoprofusion, to the prefrontal lobes, an abnormal visual evoked potential, indicating abnormalities in either the visual cortex of the brain or equal damage to both optic nerves, repeated tests showing ketoglutarate in urine and finally the blood test results which showed the infections.

Our child was a patient of 16 doctors and NONE knew what was wrong with her. We heard repeatedly "Your child's case is the most complicated case I have seen" from doctors and medical professionals with many years of experience, often the head of their departments at very famous hospitals like Boston Children's and Massachusetts General Hospital.

They did not diagnose our daughter, I did. I found Dr. Robert Bransfield's "The Neuropsychiatric Assessment of Lyme Disease". http://www.mentalhealthandillness.com/lymeframes.html "Neuropsychiatric Assessment Article" and then Dr. Brian Fallon's "Neuropsychiatric Manifestations of Lyme Borreliosis " http://columbia-lyme.org/flatp/lymeoverview.html

It took me FOUR months after I found these articles and knew what was plaguing her to find a doctor to diagnose and treat her. Many doctors would not even run new Lyme tests as she had been tested years before and results were negative. Negative test results do NOT mean the patient does not have active infection. Her tests never came back positive until she had been on antibiotics for 2 and 1/2 years. Her immune system had given up fighting the disease so there were no antibodies to show on the tests. She was bounced around from doctor to doctor. After we found a doctor to treat her I started thinking about our son and my symptoms and realized we all probably were infected. Testing and appointments with Lyme literate MDs found we all did have Lyme and other TBD.

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